Scottish Parliament Region: Glasgow

Case 200603262: Greater Glasgow and Clyde NHS Board

Summary of Investigation

Category

Health: Hospital; Neurology out patient services

Overview

The complainant (Mr C) alleged that the prescription of Pramipexole medication was inappropriate in his care and treatment for Parkinson's disease. He also complained that there was a failure in the follow-up care provided for him in the early part of 2006.

Specific complaints and conclusions

The complaints which have been investigated are that:

(a) Mr C was inappropriately prescribed Pramipexole after his care transferred to the Southern General Hospital (the Hospital) in June 2005 (*not upheld*); and

(b) there was a failure of appropriate support and monitoring of Mr C's condition during the early part of 2006 (*partially upheld to the extent that it is possible alternative support services could have been considered as part of Mr C's care*).

Redress and recommendations

The Ombudsman recommends that the Board:

(i) ensure that clear agreements, in writing if possible, are made between patients, clinicians and where appropriate, family members, about the plan of care and a patient's responsibility regarding the information expected from them during treatment; and

(ii) remind clinical colleagues of the potential referral opportunities which may be available to augment aspects of patient care and to discuss these with colleagues and patients as appropriate.

The Board have accepted the recommendations and will act on them accordingly.

Main Investigation Report

Introduction

1. On 14 June 2006, Mr C complained to Greater Glasgow and Clyde NHS Board (the Board) about the care and treatment he had received at the Movement Disorder Clinic (the Clinic) at the Southern General Hospital (the Hospital). Mr C had been diagnosed with Parkinson's disease in 2003. Up to 2005, his care was shared between two NHS areas, one in England. In 2005 the care for his condition of Parkinson's disease was transferred to the Clinic at the Hospital, bringing care under one clinical setting. The Board responded to Mr C's complaint on 19 July 2006 and Mr C remained unhappy. Further correspondence between the Board and Mr C resulted in Mr C being advised to refer his complaint to the Ombudsman. On 23 January 2007 Mr C complained to the Ombudsman that he had been inappropriately prescribed Pramipexole medication and that he did not get the appropriate support from services whilst he was under the care of a Consultant (the Consultant) at the Clinic). His main concern was that he had not been taken off the medication Pramipexole completely. Rather, the Consultant had reduced the medication gradually, with a view towards moving to complete cessation of the medication. The medication had been prescribed as part of his treatment for Parkinson's disease and Mr C considered that this medication had contributed to an episode of increased gambling, culminating in him losing a large sum of money. He said he should have been taken off the medication completely to avoid the consequences of increased gambling which he said was a well known side-effect of the medication.

2. The complaints from Mr C which I have investigated are that:

(a) Mr C was inappropriately prescribed Pramipexole after his care transferred to the Southern General Hospital (the Hospital) in June 2005; and

(b) there was a failure of appropriate support and monitoring of Mr C's condition during the early part of 2006.

Investigation

3. As part of this complaint I discussed the key issues with Mr C and received a copy of the clinical records from the Board. I have made several enquiries of the Board and have also seen the Board's complaint correspondence. I have taken independent medical advice from an adviser to the Ombudsman (the Adviser) and I am guided by him in these matters.

4. I have not included in this report every detail investigated but I am satisfied that no matter of significance has been overlooked. Mr C and the Board were given an opportunity to comment on a draft of this report.

(a) Mr C was inappropriately prescribed Pramipexole after his care transferred to the Hospital in June 2005; and (b) There was a failure of appropriate support and monitoring of Mr C's condition during the early part of 2006

5. Mr C's care was transferred to the Board on 1 June 2005 (see paragraph 1) and his care was assessed by the Consultant on 11 August 2005 after his General Practitioner (GP) referred him to the Clinic at the Hospital. At that time he was taking Pramipexole medication but in reducing amounts under the supervision of his previous Consultant. Further to the referral made by Mr C's GP on 1 June 2005 to the Clinic, in which the GP identified concern from Mr C's previous Consultant regarding some symptoms of hypersexuality and gambling, he met the Consultant and a revised treatment plan was agreed. However, Mr C was unhappy that Pramipexole was not stopped and Mr C alleged that he gambled heavily between February and May 2006 because of it. He said that once he stopped taking the medication his propensity to gamble subsided.

6. The Board said that as part of the treatment plan the Consultant followed the advice given by Mr C's previous Consultant to reduce the use of Pramipexole toward total cessation. The Board have explained that the Consultant did this in an attempt to support Mr C. The clinical notes indicated that the treatment plan to reduce the Pramipexole was supported by the use of Levadopa (Sinemet Plus), an alternative to Pramipexole. Advice was given that any other alternative medicines had similar adverse side-effects to Pramipexole and would, therefore, not be appropriate alternatives. At the same time, Mr C was encouraged to let the Clinic know of any problems he faced during this time and I have seen from the clinical notes that the matter of gambling and the reduction of the medication were frequently discussed during the out-patient clinic appointments attended by Mr C (see paragraphs 10 to 12). On Mr C’s point about the side-effects of the medication, the Board have stated that this has been an evolving field of understanding and it is now understood that compulsive pathological gambling is one example of a syndrome of compulsive behaviour. The Consultant and his team individually reviewed Mr C at different times. In the Board's comments about the draft report, they have indicated that all Mr C's consultations were fed back to the Consultant. They have stated 'The

patient's consultations were all reported to him [the Consultant] and discussed with [the Consultant] throughout the time period referred to'. In the Adviser's response to the comments made by Mr C and the Board, he has added 'while it is clear that there was a structured approach to managing his PD, [Parkinson's disease], as is common in risk-taking or compulsive behaviour caused by addiction, there is a tendency by the addicted to conceal its extent and this may have made his compliance with different medical advisors harder to monitor'.

7. The evidence in the clinical notes showed the appointments which took place between the clinicians involved in Mr C's care and there was a record of the discussion held regarding Mr C's gambling and the use of medication.

8. The clinical record showed that Mr C was seen on three occasions at the out-patient clinic during the early part of 2006; six times overall between August 2005 and May 2006. At the same time it was made clear to him that, where he felt the need to contact the Hospital to get additional support, he could do this, as could his wife. Three of the six out-patient clinic appointments were held by the Consultant and were in August and September 2005 and May 2006. Mr C was seen by the Consultant's colleagues for the remaining three out-patient clinic appointments in December 2005, January and February 2006.

9. As part of an ongoing treatment plan, reviews were held and information was sent to his GP which acted as a clinical record of the treatment plan for Mr C.

10. At the first out-patient appointment on 11 August 2005, it was recorded that the issue of gambling was discussed. Mr C advised the Consultant that he bet on horses a moderate amount and had lately started internet roulette. It was agreed that he would reduce the Pramipexole from three 0.18mg tablets three times a day initially, to two 0.18mg tablets three times a day and after one week to one 0.18mg tablet three times a day and after another week to stop. At Mr C's next out-patient appointment (14 September 2005), it was recorded that he had in fact built up the Pramipexole to 0.54mg three times a day that day. After discussion, it was recorded that Mr C had agreed that a slightly lower dosage would reduce the gambling problem and that he had discontinued betting on horses. At his next out-patient appointment on 9 December 2005, it was recorded that he was now off Pramipexole and that during a trip abroad he had not gambled. When Mr C was seen on 13 January 2006, it was recorded that he had resumed the medication and the plan was revised to try again to

support a reduction in the medication to total cessation. It was recorded that Mr C was still gambling.

11. At Mr C's out-patient appointment in February 2006, it was recorded that Mr C felt his gambling was under control, although his wife did not agree. During this appointment a more cautious approach to reducing the medication was suggested, with a view to increasing the alternative medication (Sinemet Plus) to assist in the management of symptoms. On 16 May 2006, during the next out-patient appointment, the matter of the gambling was discussed once again and Pramipexole had been stopped. It was recorded that Mr C had not been truthful about his gambling throughout the consultations at the Hospital and Mr C and his wife were critical of the service they had received. Mr C was concerned that he would not manage his symptoms of Parkinson's disease on Sinemet Plus alone but he was encouraged to maintain this plan in order to avoid the effects of Pramipexole.

12. At the appointment on 16 May 2006 it was agreed that alternative arrangements should be made for Mr C's ongoing treatment, as there was a loss of confidence in the service. The Consultant and Mr C agreed upon a referral to neuro-psychology. They also agreed that a referral to another Consultant would be appropriate and both these referrals were expedited by the Consultant on 31 May 2006. The Consultant indicated, in his out-patient clinical notes of 31 May 2006 to Mr C's GP, that he had referred Mr C to a psychology service but Mr C had expressed a preference for a referral to neuro-psychology instead and the Consultant was happy to support that.

13. During this period, a home visit from a Parkinson's Disease Nurse Specialist had been arranged through Mr C's GP, initiated by his wife. She suggested that consideration was given to psychological support and there was a discussion between Mr C and his GP about the referral to a neuro-psychologist which was agreed by the Consultant (see paragraph 12).

14. The Adviser has reviewed Mr C's clinical notes and he has said that the Consultant was following the previous Consultant's care and treatment plan to have the medication reduced to cessation; he considered that this was a reasonable course of action. The Adviser indicated that information about the possible side-effects of the medication Pramipexole, such as compulsive behaviours like excessive gambling, were not widely known at that time (August 2005 to May 2006) and have only recently started to become more

widely known in the UK. The Adviser remarked that the comments made by Mr C that information about the problems associated with the medication he was using was readily available from the internet but had not been researched or widely known in the UK at that time. He said there has been some research into the side-effects of this medication in the UK since 2003 but that the first related research papers were published in 2006. The Adviser also commented that the Consultant may not have been able to appreciate fully what Mr C was experiencing, given that the records show that Mr C did not tell him the extent to which his gambling had escalated.

15. The Adviser has said that the Consultant's approach was reasonable. He commented that the issue of gambling had been discussed with Mr C and there was no indication to think that Mr C was not in agreement with the plan to reduce and stop the medication. The Adviser has pointed out that Mr C's experience of excessive gambling is a relatively rare reaction to take and, coupled with the decision taken to continue using the medication though in reduced amounts as discussed during the out-patient clinic visits Mr C attended, he considered this to be reasonable. The Consultant was working to a treatment plan which incorporated the reduction of the medication over time, which was appropriate.

16. The Adviser highlighted that Mr C was seen by three different doctors during the period between August 2005 and May 2006 (see paragraphs 6 and 8). He said that this may have had some impact on the detection of Mr C's gambling problem. There were episodes during the care when Mr C did not comply with the decision to reduce the medication and occasions when the true extent of the gambling was not being discussed openly. The Adviser said that this may have been, in part, why Mr C's own perception of risk was not fully explored with him, which might have increased his understanding of the implications of his concealment about the level of his gambling. The Adviser has indicated that this may have contributed to missing the wider aspects of the psychiatric disturbance from the medication experienced by Mr C in relation to his change of behaviour. When responding to Mr C's complaint, the Consultant agreed that alternative opportunities for support might have been considered earlier but said that Mr C's clinical presentation did not lead him to that conclusion at the time.

17. The Adviser has agreed that it might have been helpful to suggest additional support for Mr C during the clinic appointments in December 2005 or

in February 2006. However, he has said that it is not possible to conclude this would have been definitive in resolving Mr C's problem. It is understood the only resolution to the problem of his propensity to gamble and to avoid the problem for him and his family was likely to have been to stop the medication, which is what the Consultant was working toward. The medication reduction was being carried out in good faith with the understanding that Mr C was complying with it. This was found not to have been the case and regrettably Mr C kept the true extent of the gambling problem from the clinicians. Additionally, Mr C has commented that the view of his wife at the out-patient appointments regarding the extent of Mr C's level of gambling was not fully appreciated.

(a) Conclusion

18. The evidence has shown that Mr C was encouraged to reduce his intake of Pramipexole to a point of total cessation (see paragraphs 10 to 12). This matter had been discussed prior to Mr C's referral to the out-patient clinic in the Hospital by his GP. The Consultant was aware of the matters raised in the referral letter and embarked on a treatment plan to support the reduction of the intake of the medication, Pramipexole, to a point of stopping completely. Whilst it is clear from the records that the issue of Mr C's gambling was discussed, the advice I have received is that Mr C did not tell the Consultant the extent to which his gambling had escalated and that, during episodes of care, Mr C did not comply with the decision to reduce the medication. The Adviser has concluded that the actions of the Consultant were reasonable and I have to be guided by this advice. Taking into account all the information that has been made available to me, therefore, I do not uphold this aspect of the complaint. However, given the misunderstanding which developed between the clinical staff and Mr C regarding the extent of his gambling and the information that is expected from patients in treatment, the Ombudsman has the following recommendation to make.

(a) Recommendation

19. The Ombudsman recommends that the Board ensure that clear agreements, in writing if possible, are made between patients and clinicians about the plan of care and a patient's responsibility regarding the information expected from them during treatment.

(b) Conclusion

20. Mr C complained that he was not given an appropriate level of support in terms of the opportunities available in the Clinic and with the community nursing service. The advice I have received is that staff did not pick up on the extent of Mr C's gambling beyond the information they were being given. The Consultant also acknowledged that he could have referred Mr C to other available support services (see paragraph 16). However, while the Adviser has indicated Mr C was seen by a number of clinicians, which did not help the detection of the gambling problem, and it may have been helpful to suggest additional support, this might not have been definitive in resolving Mr C's problem (see paragraph 17). In this respect, therefore, the advice I have received is that possible alternative support services could have been considered and, to this extent, I partially uphold this aspect of the complaint.

(b) Recommendation

21. The Ombudsman recommends that the Board remind clinical colleagues of the potential referral opportunities which may be available to augment aspects of patient care and to discuss that with colleagues and patients as appropriate.

22. The Board have accepted the recommendations and will act on them accordingly. The Ombudsman asks that she is advised of the way the recommendations are implemented.

Annex 1

Explanation of abbreviations used

Mr C	The complainant
The Board	Greater Glasgow and Clyde NHS Board
The Clinic	The Movement Disorder Clinic
The Hospital	Southern General Hospital
The Consultant	Consultant Neurologist
The Adviser	Independent adviser to the Ombudsman
GP	General Practitioner

Annex 2

Glossary of terms

l-dopa (Levodopa)	An intermediate in dopamine biosynthesis. In clinical use, levodopa is administered in the management of Parkinson's disease
Parkinson's disease	A degenerative disorder of the central nervous system which often impairs the sufferer's motor skills and speech
Pramipexole	Medication indicated for treating Parkinson's disease
Sinemet Plus	A combination of carbidopa and levodopa for the treatment of Parkinson's disease and syndrome